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ABSTRACT

This final report describes the outcomes of Project Apache, a reservation, community-based early intervention program designed to develop comprehensive services to Apache infants and toddlers who are at risk of developing a disability and their families. The project uses a home-based service delivery program with paraprofessional aides to assist in implementing the family intervention plan. A reservation-based referral process was put into place with the cooperation of the Indian Health Service to identify at the earliest possible time infants who are at-risk for becoming developmentally delayed. Family and child assessments are used that are more dynamic and ongoing, as opposed to linear and sequential. The project found that formal assessment instruments were ineffective in working with the White Mountain Apache families and that information should be obtained through informal interviews and observation. The paraprofessionals were found to be very effective at securing this information. A list of recommended developmental assessments is provided, along with a list of successful interventions. The report describes the referral process, assessments, development of Individualized Family Service Plans, interventions, and program evaluation. Recommendations for providing services to Indian populations are made throughout the report. (CR)

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Project Apache

A reservation, community-based early intervention program for Apache infants and toddlers with special needs and their families

A Handicapped Children's Early Education Program Project

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Historical Overview

Head Start Program. The Fort Apache Reservation has had a history of services to young children through the commitment of the Tribe to the Head Start program. Currently, the Head Start program serves children who are four and five years of age. At least 10% of the children served must have been identified as handicapped. Mr. Catron, Director of the Head Start, has estimated that as many as 15-20% of the children served by the Head Start program are handicapped in some way.

Institute for Human Development–Northern Arizona Child Evaluation Center (NACES). The Northern Arizona Child Evaluation Center was established at Northern Arizona University by the Arizona Department of Education in 1975 to serve as one of three regional Evaluation Centers. The purpose of the Evaluation Centers is to provide screening and multi-disciplinary evaluations to children from birth to twenty-one years of age who are experiencing a barrier to education and need to be diagnosed as in need of special education services.

The NACES professional team has conducted field-based evaluation clinics for the last 14 years across northern Arizona. At least one multidisciplinary clinic has been conducted in Whiteriver each year. It is through this program that children began to be identified as handicapped and in need of special services. Most of the children who have been seen were below school age.

Institute for Human Development–Paraprofessional Outreach Program. In addition to the NACES Program, the Institute for Human Development began a Paraprofessional Outreach Program on the Fort Apache Reservation in 1980. The purpose of the Outreach Program was to identify and serve children under six years of age who were developmentally delayed. Funding for this program was provided by the Arizona Division of Developmental Disabilities. A limited amount of funds were provided to begin services consisting of educational and therapeutic interventions.

A "Paraprofessional" model of services has been used. This consists of hiring and training local individuals who have not had formal training as early interventionists to implement educational and therapeutic (physical and speech/language) plans in the homes of identified children under the monthly supervision of a special educator. The special educator travels from Flagstaff once a month to monitor child progress and supervise the local staff.

Over the last nine years, over 60 families have been served through this model.

Institute for Human Development–Preschool Handicapped Classroom. In 1986, the Institute for Human Development (IHD) secured additional funds through the Arizona Department of Education, Office of Special Education, in order to develop and operate a preschool classroom for children between the ages of 3-5 who were identified as handicapped. The classroom site was at the Head Start Center in Whiteriver and

Cibecue. Paraprofessional staff were then trained to conduct group classroom activities, in addition to individual instruction using a preschool classroom environment. In 1986, the IHD assisted the Whiteriver Public School in applying and securing the funds to continue the operation of a preschool handicapped program in Whiteriver and Cibecue. This program is currently operated in conjunction with the Head Start program. There is no waiting list. The program has had high visibility and local community service agencies are aware of its operation. Referrals come from the Indian Health Service and word-of-mouth.

Institute for Human Development–Project Apache. Most recently, the IHD secured a federal grant through the U.S. Department of Education, Office of Special Education, Handicapped Children's Early Education Program, to develop comprehensive services to infants and toddlers who are at risk for developing a handicapping condition and their families. Over the last three years, services to this population were developed and have greatly increased. There are currently 16 families being served.

Summary. The Institute for Human Development at Northern Arizona University has a significant history of program development on the Fort Apache Reservation as it relates to the development of special education services to young children and their families from birth to five years of age. The model that will be described in the subsequent section was designed with this kind of historical experience with the White Mountain Apache people and government. Certain program elements that have been used and are recommended to be continued are based upon an understanding and knowledge of the culture--the traditions, beliefs and practices of the White Mountain Apache people.

Early Intervention Program Description

The service model was developed to be in compliance with Part H, P.L. 99-457. Part H labels services to children from birth through two years of age as "early intervention". Since the Whiteriver Public School preschool handicapped program in conjunction with the Head Start program is currently meeting the identified needs of children between the ages of three to five years, the BIA's participation in solidifying the program offerings for children from birth through two years of age would insure a service delivery system in the White Mountain Apache communities for all eligible children below six years of age. The federal funding for model development which resulted in the current services for children under three years of age in the Fort Apache area is due to terminate this Fall (services through this source of funding will be discontinued at the end of June, 1989).

The following information describes the service delivery model that has been developed for this Reservation, and found to be effective in meeting the needs of infants and toddlers who are developmentally delayed, or at risk of developing handicapping conditions, and their families.

The model to be described has been developed over the last three years by IHD

experts in the field of early intervention to young children who are handicapped and their families. The intervention parallels the process for special education, with the exception that family intervention is a major component, as required by Part H, P.L. 99-457. The assessment instrumentation and curriculums have been chosen because of their effectiveness with this target population. It is a home-based service delivery program, using paraprofessional aides to assist in implementing the family intervention plan.

The Referral Process

A Reservation-based referral process has been put into place with the cooperation of the Indian Health Service. In order to identify infants who are at-risk for becoming developmentally delayed or handicapped at the earliest possible time, Dr. Brewer, IHS pediatrician, screens birth information of all newborns for characteristics that place them at-risk for developmental delays. Appendix A consists of the High-Risk Index that is used by Dr. Brewer to identify infants for referral. This Index was developed after an extensive review of the professional literature and in conjunction with IHS physician input. It represents the best professional estimate of the kinds of early biological conditions that place infants at risk for future developmental problems. Infants with neonatal conditions that have a known probability for resulting in developmental delays are also included, such as Downs Syndrome.

Dr. Brewer indicates on the form and in a memo the reasons for referral to the early intervention program, which has been known as Project Apache. During the last two years, both the IHS Community Public Health nurses, and the tribal Community Health Representatives have been used to secure parental permission to refer the family to Project Apache. Appendix B consists of the referral form that is used to secure this parental permission. With the pending interagency agreement between the BIA and the IHS, referrals may be able to flow directly from Dr. Brewer to the BIA Project Coordinator. This would facilitate the referral process for families.

In addition to newborn referrals, the public health nurses and IHS physicians can screen and refer any child who at other points in their development begin to show signs of potential developmental problems. The IHS is an integral part of the referral system and should be included as a member of the "team" of professionals delivering this program.

In addition to the IHS referrals, the existing referral system includes referrals from parents themselves, family members, friends, Head Start personnel and school personnel.

There will be a need for the Special Educator to foster the continuance of this referral system by meeting with individuals who are in a position to make referrals, conduct training regarding how to make appropriate referrals, and create public awareness of the program.

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Family and Child Assessments

Under Part H, assessments of both the family and child needs must be conducted. A process has been developed which consists of the special educator initiating the early intervention services by beginning an assessment of the family needs first. Upon receipt of a referral, a home visit is scheduled which initiates the assessment process. (This process should not ignore that most newborn referrals consist of biological risk conditions which require medical interventions. The medical interventions begin at the time of delivery, and must be taken into consideration by the special educator as their responsibilities related to home-based interventions begin).

Family and child assessment under Part H is different from the traditional special education assessment process. It is more dynamic and on-going, as opposed to linear and sequential. Both the family needs and the infant needs change radically during the first year of life, depending upon the condition of the infant and the stability of the family.

An "extended" diagnostic period consisting of up to 3 months of interactions with the family and child is used to conduct the assessment of the family and baby needs. In order to effectively assess family needs, an initial period of time (approximately one month) should be used to begin to build trust and confidence between the project staff and the family members. Project staff must develop the skills to do active listening and informal interviewing. They should get to know the baby and the primary caregiver, as well as other significant family members.

The purpose of early intervention is to enhance the caregiving environment of the child in order to maximize developmental potential.

Family assessments. The family assessment process should result in information about: (1) family formal support needs, (2) family informal support needs, (3) the safety of the caregiving environment, (4) the health status of the primary caregivers, (5) other family problems likely to adversely affect the caregiving environment, (6) family members' specific concerns about the baby.

1. Family formal support needs consist of considerations regarding the level of the family income, food supplement needs, medical care needs, social service needs, etc. Informal checklists can be used to document information related to this area (see Appendix C). Information regarding these needs should be obtained in a relaxed, trusting environment when the caregiver feels comfortable with the Special Educator or Instructional Aides so that they will share this information. Many families are extremely private people, and may choose not to discuss this information.

If, however, it is determined that there are basic unmet needs within the family that existing service agency programs can address and the family indicates that they desire assistance in securing these program services, the Special Educator should document the needs and begin family intervention (to be discussed in a subsequent section).

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Examples of existing formal support programs for families are the WIC program, AHCCCS, CRS, AFDC, etc.

2. Informal support needs consist of situations in the social-emotional and familial environment that have been identified through research as critical to the developmental outcome of the infant. This consists of issues like having someone to talk to on a regular basis when you have a problem, having access to babysitters, getting time out of the house for yourself and/or spouse, getting financial assistance for emergencies from families and friends. It is the support system that helps families function in a healthy matter.

Although there are formal assessment instruments that have been developed for use in this area, we found that they were ineffective in working with the White Mountain Apache families. This information should be obtained through informal interviews and observations. The Instructional Aides are very effective at securing this information.

The Intervenor should not force families to provide this information. It must be secured over a period of time as you begin to get to know the family. Interventions should be planned to address needs that the family identifies for assistance.

3. The safety of the caregiving environment should be unobtrusively assessed. Many of the homes have not been prepared for the young infant. Appendix D represents a Safety Checklist that was developed by Project Apache. It should be administered and filled out in order to identify ways to improve the safety of the child's environment. This is often one of the first interventions that will need to be done.

For instance, we noticed that a newborn baby was being placed in a crib without any sides over a concrete floor. We recommended to the mother that she ask the father to put sides on the crib so that the baby would not fall out and get a head injury. The next week the sides had been placed on the crib.

4. The health status of the primary caregiver is important. The Special Educator should continually conduct informal observations of the physical and mental health status of the caregiver. For instance, post-partum depression may be seen. The mother may be undernourished or experience physical problems due to a problem pregnancy. There may be drug abuse or chemical dependency occurring.

These are important considerations because there is growing evidence that the early caregiving environment is extremely important from the newborn period on. Infants of depressed mothers exhibit "depressed" behaviors, such as low affect, fewer vocalizations, passive movements, etc.

5. There may also be problems that other family members are having, such as depression due to job loss, or alcoholism. Their behavior in the home will also affect the babies development. Once again, assessing the family needs in this area should be done through informal observations and conversations. Many of the families will choose to hide problems related to alcohol and not want to talk about it.

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6. Finally, the Special Educator should be sure to understand what concerns the caregiver and other family members have regarding their baby. It is often times different from the concerns of the professional. Before the professional determines what the baby's needs are, they should consciously listen to the family members and address their concerns first, or concurrently, whenever possible.

It is primarily through the process of active listening and informal interviewing that this information can be effectively obtained. One mother we worked with was afraid her child was blind. She had not told us that, however, until the child was assessed on her visual tracking abilities. The mother could then tell that the baby could indeed see, and remarked that she had been afraid that the baby could not see. This unspoken fear of the mother's had, no doubt, created quite a bit of anxiety, and ultimately might have been effecting her caregiving behaviors.

Another mother we worked with was concerned about keeping the baby in clean clothes because the baby drooled a lot, messed on her clothes all the time, yet the mother did not have running water. This was a real, viable need as identified by the mother that was then addressed through an intervention activity. (We changed the bottle nipple to reduce leakage around the mouth).

Child assessments. Educational assessments of the child's developmental status should be conducted on a quarterly basis during the first year of life. During the second year of life, assessments may be appropriate using a semi-annual schedule. Therapeutic assessments (physical/occupational therapy and speech/language therapy) should be identified and conducted on an individualized basis, depending on the child's problems. All children should be screened for potential vision and hearing problems within the first three months upon entry into the program.

Comprehensive evaluations in all developmental areas should be determined based upon the child's specific problems. The Special Educator will have the responsibility for determining the nature of the educational child assessments that should be conducted, both for identification purposes and for programming purposes. Appendix E provides a sample of a completed evaluation of the family and child needs.

The following assessment instruments are recommended:

1. Nursing Child Assessment Training Instruments. The University of Washington has developed an assessment of the feeding and teaching environment of the infant. The nature and quality of the interaction between the primary caregiver and the infant is observed. Information from the assessments can be used to identify positive and absent parenting behaviors known to influence positive child growth and development. Interventions can be planned using the test items as objectives.

An assessment of the home environment can also be conducted using the HOME, developed by Dr. Bette Caldwell at the University of Arkansas. Information from this information has been found to correlate with later intellectual development.

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The IHD has several professionals who are trained and certified to administer these tests.

2. Bayley Scales of Infant Development. This instrument is recognized most frequently by the field as a valid, standardized assessment instrument. Its predictability increases with the child's age. It can be used for diagnostic purposes. A mental age is obtained as a standardized score. It requires a trained professional for administration. (IHD professionals can administer this).

3. Carolina Curriculum for Handicapped Infants. This is a criterion-referenced assessment of the child's abilities with a curriculum guide suggesting activities and interventions for teaching targeted skills. It was developed at the University of North Carolina. It can be used for diagnostic purposes to determine the % of delay exhibited by the child at the time of testing, as an evaluation tool to monitor child progress, and as an intervention guide. It is typically administered by the primary intervenor (such as the special educator).

The IHD can train the project Special Educator to use this tool. In addition, IHD staff have rewritten the original curriculum. It now contains activity considerations for cultural appropriateness, alternative suggestions for materials that can be found in Apache homes, and reduced written language comprehension requirements.

Summary. The above child instruments would constitute the primary battery that would be used to conduct educational child assessments. Additional instrumentation would be selected by the related services personnel on an as-needed basis.

Individualized Family Service Plan

Based upon the assessment information, which will extend up to three months in time, the Individualized Family Service Plan can be written. (Interventions with the family really begin the day of the first home visit. The Special Educator and Instructional Aides will begin assisting the family in many ways as immediate needs are determined. However, in compliance with the P.L. 99-457, a formalized plan must be agreed upon between the family and intervenor, written up, and approved by the primary caregiver/family.)

Within three months of the referral, the IFSP will be approved. A sample of an IFSP can be found in Appendix E. This is similar to an IEP, except that information about the family must also be included. The IFSP will be designed with the input of the family, selecting priority needs that are the family's priority. The clear exception to this policy, is the identification by project staff of a health or safety need related to the child. This must be immediately addressed by the project staff with the family. However, whenever feasible, the project staff will attempt to find a way to intervene in a matter that is consistent with family input.

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It is recommended that during the first two years of life, the IFSP be reviewed semi-annually, in order to be optimally responsive to the changing needs of the family and child.

Interventions

As indicated earlier, interventions begin at the same time as assessments begin, which is at the point of the first home visit. Because intervention is conducted in the families' homes, it is impossible to participate in the family environment without having some kind of impact upon that family. Any suggestions that are made, material that is provided, or education that occurs while interacting with the family constitutes intervention.

Home visits. The frequency of the home visits should be determined jointly with the family. Twice/week visits will be appropriate for many of the families. However, the schedule will vary depending upon need, and is likely to change as the baby changes. For children less than one year of age, it is recommended that a minimum frequency of visits be established as once/month, with most families receiving weekly visits.

During the second and third year of life, assessments may indicate that the child is developing within normal range, the caregiving environment may be stable and healthy, and the intervention may consist of quarterly follow-ups. Other children, however, should continue to receive weekly home visits.

Because of the highly individualized nature of services to this age population, the program must reflect flexibility in meeting individual needs.

Coordination of community activities. The Special Educator will participate in the BIA coordinated Interagency Committee. In addition, they will establish a professional relationship with each of the service providers in the communities, region, and state where necessary. It will be the Special Educator's role to facilitate family access to needed services.

Toy lending library. The project staff will operate a toy lending library for the participating families. Age appropriate toys will be purchased and organized for lending to the families. The families may select items to be used in their homes for short periods of time. The project staff will train the parents on how to use the toys in order to maximize the development of the child. The toys will provide variety of stimulation for the children in their homes.

We have found the toy lending library concept to be the most requested service we can provide for the families.

Parent workshops. Early intervention consultants from the Institute for Human Development will be responsible for planning and conducting monthly parent workshops. During the last year the parent workshops have been extremely successful and highly

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attended. Some of the past activities have included: (1) making sock toys; (2) participating in the annual health fair by conducting a play dough making activity; (3) Christmas party; and (4) jobs fair.

The consultants will review the parent education needs that have been identified by the Special Educator and jointly decide the kinds of activities, format, topics that will be selected for each month. The consultants will also meet individually with parent's upon request to answer any specific child development and parenting questions they may have.

In addition, the consultants will assess the feasibility of developing respite care services on the Fort Apache Reservation through the Arizona Division of Developmental Disabilities.

Transition. A transition plan will be included in each child's IFSP during their third year (age 2) in order to insure a smooth and coordinated transition from infant/toddler program to the preschool services (public school and Head Start). The Special Educator will arrange evaluations of each of the children who will be transitioning in order to determine eligibility for services, if necessary. The Special Educator will also arrange meetings with the receiving agencies and the families to discuss placement and transitioning issues.

Program Evaluation

The instrumentation and strategies that have been delineated lend themselves easily to annual program evaluation activities.

First, information from the child assessments can easily be used to document developmental progress of the children.

Secondly, family interventions can be quantified in terms of the type and frequency of different services that the family is now receiving because of the project interventions, positive changes in parenting behaviors (as documented by the interactional and environmental assessments), participation in parent workshops, anecdotal comments by the families regarding changes in the family functioning because of project involvement, etc.

Public awareness activities will be conducted by the Special Educator in order to keep the communities informed of the activities and improve child and family access to the program.